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COPING WITH STRESS AND ADAPTATION IN MOTHERS OF CHILDREN WITH CEREBRAL PALSY

PREVLADAVANJE STRESA I ADAPTACIJA MAJKI DECE S CEREBRALNOM PARALIZOM

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Summary

Introduction. Raising a child with cerebral palsy is stressful for the parent because it requires an intensive physical engagement as well as coping with emotional reactions to the child's condition. Parents have different modes of adapting to stress and demands caused by the disorder. The Resiliency Model of Family Stress, Adjustment and Adaptation postulates that the use of certain coping strategies facilitates successful family adaptation to the child's condition. **Material and Methods.** Our study included 60 mothers of two- to seven-year-old children with diagnosed cerebral palsy. The modified *Family Crisis-oriented Personal Evaluation Scales*, with its five sub-scales, was applied to assess the strategies used by families to cope with stress. **Results.** The most frequently used strategy is reframing, whereas other strategies were used less frequently. The study has revealed some differences in adoption of certain strategies by mothers from urban and rural areas as well as of those strategies which depend on the severity of the child's condition. **Discussion.** The fact that reframing is the most frequently used strategy is encouraging because it helps parents to make their grave situation more acceptable. Institutional support is also often used by mothers of children with severe form of disease because of their need for medical care. **Conclusion.** Recognition of coping strategies of the parents is important and useful for the development of therapeutic interventions aimed at facilitating family adaptation in families with a child with developmental disabilities.

Key words: Stress, Psychological; Adaptation, Psychological; Mothers; Parents; Child; Child, Preschool; Cerebral Palsy; Social Support; Resilience, Psychological

Introduction

In addition to usual demands imposed by the parenthood, families with a child with developmental difficulties face a series of specific tasks arising from the child's health condition [1]. Numerous studies have shown that specific physical demands and experience of disappointment because of health problems of the child cause stress in parents [2-5].

Sažetak

Uvod. Podizanje deteta s cerebralnom paralizom uzrokuje kod roditelja stres izazvan potrebom za izraženim fizičkim angažovanjem oko deteta, kao i emocionalnim reakcijama na detetovo stanje. Postoje varijacije u tome kako se roditelji prilagođavaju na stresore i zahteve izazvane detetovom bolešću. Model porodične rezilijentnosti, regulacije i prilagođavanja pretpostavlja da korišćenje određenih strategija prevladavanja stresa olakšava uspešnu porodičnu adaptaciju na detetovo stanje. **Materijal i metode.** U istraživanje je bilo uključeno 60 majki čija su deca uzrasta od dve do sedam godina. Korišćena je modifikovana *Family Crisis-oriented Personal Evaluation Scales*, koja preko svojih pet supskala procenjuje strategije koje koristi porodica da bi prevladala stres. **Rezultati.** Strategija redefinisavanja izdvojila se kao najčešće korišćena strategija, dok su ostale strategije korišćene umereno često. Dobijene su i razlike između korišćenja određenih strategija kod majki iz gradske i seoske sredine, kao i u korišćenim strategijama u zavisnosti od same težine bolesti deteta. **Diskusija.** Izdvajanje redefinisavanja kao najčešće korišćene strategije jeste ohrabrujući podatak jer ona pomaže da roditelji svoju tešku situaciju redefinišu, kako bi je učinili smislenijom i prihvatljivijom. Takođe je bitno korišćenje institucionalne podrške kod majki dece s teškim oblikom bolesti zbog njihove potrebe za učestalom medicinskom brigom. **Zaključak.** Znanje o strategijama koje porodicama pomažu u prevladavanju stresa izazvanog detetovom bolešću veoma je važno za praktičnu delatnost. Ono pomaže razvoju terapijskih intervencija koje će promovisati aktivnosti i načine prevladavanja stresa koje olakšavaju porodičnu adaptaciju.

Glavne reči: Stres, psihološki; Adaptacija, psihološka; Majke; Roditelji; Dete; Predškolsko dete; Cerebralna paraliza; Socijalna podrška; Rezilijentnost, psihološka

Stress of caregiving and raising a child with developmental difficulties is seen as a combination of increased needs for the child care and emotional reactions caused by the child's condition [6].

One of the most difficult problems for a family is the birth of a child with physical impairment or the development of a disability during early childhood [7]. Cerebral palsy (CP) is the most common severe disability affecting children, with preva-

Abbreviations

CP – cerebral palsy/cerebralna paraliza

lence of 2 to 3 cases per 1000 live births [8]. CP is a syndrome of non-progressive, motor impairment resulting from lesions or anomalies of the brain at the early stages of its development [9]. An impaired motor function is the hallmark sign of CP, but many children also have sensory, communicative and intellectual impairments, and may have complex limitations in self-care functions, such as feeding and dressing up [10]. Epilepsy is a common co-morbidity [11]. CP influences not only the child's everyday functioning but also the functioning of the whole family [12,13]. Some studies have found a correlation between severity of the child's condition and worse family functioning, but other studies have not replicated this direct relation [14].

Medical risks and neurological effects associated with CP are clearly defined, but psychological effects and coping strategies in families with a child with CP have not been fully analyzed [9]. The question to be answered is how some parents successfully cope with this stressful situation and some parents do not [10,15]. The Resiliency Model of Stress, Adjustment and Adaptation [16] attempts to answer „why some families are resilient (able to cope) and recover from crisis and other stay vulnerable or deteriorate”. This model is a framework for the assessment of the processes of family coping of stress caused by raising a child with a chronic illness or developmental disability [4,17]. Resiliency is defined as the capacity to adapt and overcome adverse situations and circumstances. The resiliency model assumes that efficient family coping facilitates positive family adaptation [18]. Coping refers to manifest or latent efforts which family or some of its members make to deal with the problem. Strategies used by families can serve as an indicator of adaptation to child's chronic disease [7].

Family coping strategies resulting from the Resiliency Model of Stress, Adjustment and Adaptation involve two levels of interaction: 1) interaction between the individual and the family system (internal strategies) and 2) interaction between family and social environment (external strategies) [16]. Reframing personal and family priorities (internal strategy) helps the parents to cope with their child's illness. Passive appraisal (internal avoiding strategy) may reduce stress for short time, but it leads to maladaptive family functioning [19]. Several studies have shown the positive impact of social support on parental adaptation to the child's condition [2,13]. The level of social support in the early period after learning about the child's health condition is crucial, and it can affect both short-term and long-term coping and adaptation of parents [20]. Every form of support is important – both informal, such as relatives, friends and neighbors, and formal (institutional) support [21,22].

Birth of a child with special needs changes the functioning of the family. If these changes are accompanied by unsuitable coping strategies, they may result in disturbed marital and other family relation-

ships as well as professional relations, which lead to further anxiety in the family [5].

This study was aimed at examining the coping strategies used by mothers of children with cerebral palsy.

Material and Methods

The research was conducted at the Institute for Child and Youth Health Care of Vojvodina in Novi Sad. Sixty mothers of children with diagnosed cerebral palsy, aged 2 to 7 years, participated in the study. The average age of mothers was 32 years; 65% of them had high school level of education, 25% had a faculty degree, and 10% finished only elementary school. Fifty-five % of mothers were from rural and 45% from urban areas. Forty-seven % of children whose mothers participated in the study had mild form of CP, 18% moderate form, and 35% have severe form of CP.

F-Copes (Family Crisis-oriented Personal Evaluation Scales) was used as a measure of family coping [23]. It is an instrument designed to show problem solving behaviors and strategies used by families when facing difficulties and crisis. It measures coping strategies defined in the Resiliency Model of Stress, Adjustment and Adaptation [16]. We used a modified version of the scale, adapted to our population by M. Mitić [24]. It consists of five subscales: acquiring social support, reframing, seeking spiritual support, mobilizing family to seek and accept help and passive appraisal.

General Demographics Questionnaire included data about age, level of education and place of residence (rural or urban).

The severity of child's condition was defined by several objective criteria, with respect to child's age: motoric deficit, psychomotor development coefficient and self-care ability. The children were categorized as having a mild, moderate or severe form of disorder according to these criteria.

The data were analyzed in statistical software SPSS 11.0, using descriptive statistics and one-way ANOVA (one-way analysis of variance).

Results

Table 1 presents the use of the strategies expressed as mean of the scores on each subscale. It also shows the minimum and maximum scores on each upscale – 1 represents "very often" and 5 represents "never".

The results show that all strategies are used moderately often (sometimes), except for reframing, which is a more often used strategy. The score dispersion shows that some mothers never use seeking of spiritual support or institutional support, and that none of the mothers use social support very often.

One-way analysis of variance examined the differences in the use of strategies between the mothers

Table 1. Frequency of the use of coping strategies**Tabela 1.** Učestalost korišćenja strategija prevladavanja

	Minimum <i>Minimum</i>	Maximum <i>Maksimum</i>	Mean <i>Aritmetička sredina</i>	Standard deviation <i>Standardna devijacija</i>
Acquiring social support/ <i>Socijalna podrška</i>	2.33	4.78	3.40	.59
Reframing/ <i>Redefinisanje</i>	1.09	3.09	2.04	.38
Seeking spiritual support/ <i>Duhovna podrška</i>	1.25	5.00	3.45	.85
Institutional support/ <i>Institucionalna podrška</i>	1.50	5.00	3.05	.76
Passive appraisal/ <i>Pasivna procena</i>	1.83	4.33	3.22	.50

Table 2. Differences in coping strategies between mothers from urban and rural setting**Tabela 2.** Razlike u strategijama prevladavanja majki iz gradske i seoske sredine

	Residence <i>Prebivalište</i>	Mean <i>Aritmetička sredina</i>	Standard deviation <i>Standardna devijacija</i>	F	Level of significance <i>Nivo značajnosti</i>
Acquiring social support <i>Socijalna podrška</i>	Urban/ <i>Grad</i>	3.47	.61	.719	.400
	Rural/ <i>Selo</i>	3.34	.57		
Reframing <i>Redefinisanje</i>	Urban/ <i>Grad</i>	2.08	.30	.629	.431
	Rural/ <i>Selo</i>	2.01	.44		
Seeking spiritual support <i>Duhovna podrška</i>	Urban/ <i>Grad</i>	3.50	.97	.140	.709
	Rural/ <i>Selo</i>	3.42	.75		
Institutional support <i>Institucionalna podrška</i>	Urban/ <i>Grad</i>	3.17	.62	1.242	.270
	Rural/ <i>Selo</i>	2.95	.86		
Passive appraisal <i>Pasivna procena</i>	Urban/ <i>Grad</i>	3.39	.47	5.640	.021
	Rural/ <i>Selo</i>	3.09	.49		

from urban and those from rural areas. The results are presented in table 2 (**Table 2**).

The only statistically significant difference between mothers from urban and rural areas is in the use of passive appraisal – mothers from rural areas use this strategy more often. No differences were found in the frequency of the use of other strategies. Therefore, it can be concluded that there is no differ-

ence in the use of social support, reframing, seeking spiritual and institutional support by mothers from different areas (rural and urban). Having examined the differences in coping strategies among mothers considering the severity of their child's disorder, we have concluded that there is no difference in the use of social support, reframing, spiritual support and passive appraisal. The difference is found in the use

Table 3. Coping strategies depending on the severity of the child's condition**Tabela 3.** Strategije prevladavanja u zavisnosti od težine bolesti deteta

	Severity of the condition/ <i>Težina bolesti</i>	Mean/ <i>Aritmetička</i> <i>sredina</i>	Standard deviation <i>Standardna devijacija</i>	F	Level of significance <i>Nivo značajnosti</i>
Acquiring social support <i>Socijalna podrška</i>	Mild/ <i>Blag</i>	3.41	.61	.536	.588
	Moderate/ <i>Umeren</i>	3.55	.63		
	Severe/ <i>Težak</i>	3.32	.54		
Reframing <i>Redefinisanje</i>	Mild/ <i>Blag</i>	3.41	.44	1.288	.284
	Moderate/ <i>Umeren</i>	2.07	.35		
	Severe/ <i>Težak</i>	1.93	.29		
Seeking spiritual support <i>Duhovna podrška</i>	Mild/ <i>Blag</i>	3.41	.91	.630	.536
	Moderate/ <i>Umeren</i>	3.66	.91		
	Severe/ <i>Težak</i>	3.31	.74		
Institutional support <i>Institucionalna podrška</i>	Mild/ <i>Blag</i>	3.49	.62	4.030	.023
	Moderate/ <i>Umeren</i>	3.14	1.12		
	Severe/ <i>Težak</i>	2.69	.60		
Passive appraisal <i>Pasivna procena</i>	Mild/ <i>Blag</i>	3.41	.48	.141	.868
	Moderate/ <i>Umeren</i>	3.18	.51		
	Severe/ <i>Težak</i>	3.20	.55		

of institutional support – mothers of children with severe forms of CP seek institutional support more often than mothers of children with moderate forms, while mothers of children with mild forms of CP seek this support rarely (**Table 3**).

Discussion

The results of this study suggest that reframing is the most often used strategy in the families with a child with CP. The results of previous research were ambiguous: although some of them showed that reframing was under-utilized strategy by mothers of children with CP [24], others found that mothers of elementary-school aged children with CP used reframing often and associated it with more successful adaptation [4]. Our results show that mothers of even younger children often use reframing as well. This result is encouraging, because this strategy helps parents in cognitive reconstruction of difficult, painful and highly undesirable situation, making it more meaningful and therefore more acceptable. The parents perceive stressors as an inevitable part of life, and reframing enables them to redefine these stressors in a more positive way in order to find solutions for problems they are facing instead of being discouraged by them.

Another frequently used strategy is seeking institutional support in the sub-sample of mothers with children with a severe form of disorder. These parents and their children are the ones who are often referred to various medical procedures and they are the most frequent users of medical services. Research has confirmed the importance of professional help for successful implementation of the role of caregiver for the child with CP [10]. Their parents should be encouraged to use this form of support, but we also need to ensure proper quality in terms of proper professional services. The observation that parents of children with mild forms of CP do not use institutional support is important and has to be taken into further consideration. It is necessary to link parents with the institution. Integration of family as a part of the rehabilitation team is an imperative for success, especially for the children with CP. The comparison of the mothers who live in rural and urban areas shows that the difference is in more frequent use of passive appraisal by the mothers from rural areas, which reflects a certain passivity and "resignation to fate." Other studies have also confirmed the frequent use of passive appraisal among the mothers whose children have not only CP but other developmental disorders as well [19,24]. Passive appraisal may be based on the belief that parents have no ability to change the circumstances caused by the child's handicap. However, perception of their own ability to influence the outcomes related to the child's condition positively provides a healthier and more successful adaptation of par-

ents of sick children [5]. Given that in our country it is often very difficult for people from towns and villages to obtain ongoing support (in the form of associations, day care for children, professional work with them), this result is not surprising, and should be considered in the light of socio-economic situation in which these families live. Another important finding of our study is that a large number of mothers never use strategies such as spiritual support. Although the importance of spiritual support was repeatedly confirmed in previous research [4], other studies have also shown its lower use [19]. In contrast to studies indicating the importance and frequent use of social support [10,13], our research has indicated that this strategy is not used often enough. Considering their importance, it is necessary to promote the use of these strategies for coping with stress through preventive programs for parents of children with developmental difficulties.

Although raising a child with disabilities includes many difficulties, many parents still report high levels of satisfaction and pleasure in this role [5]. The knowledge of the factors associated with resilience in these families can improve the effectiveness of therapeutic interventions. It is clear that child's health condition has a huge effect on the family, but some families have greater capacity for coping, while others need more support in order to adapt successfully. Therefore, this research field represents the cooperation between scientific studies and practice of those who work with the children with developmental disabilities and their parents. It is necessary to develop interventions aimed at reducing stress in these parents. The contribution would be in improving psychosocial care for children and families and the guidance and assistance in coping with stressful conditions caused by the chronic health condition of the child. Interventions need to focus on family strengths, which are emphasized and seen as resources which lead individuals to overcome adversity [25]. Reliance on existing resources and helping the family to reorganize their ways of functioning is an important task for practitioners who work with them [17].

Conclusion

Research focused on coping strategies provide an insight into desirable strategies which contribute to more successful family adaptation. Our study singled out reframing as the most frequently used coping strategy in families of children with cerebral palsy. Families with a child with severe forms of cerebral palsy also frequently use institutional support, which is a strategy less often used by parents of children with mild forms of cerebral palsy. Mothers from rural areas use passive appraisal more often. All parents from our sample tend to seek spiritual and social support less frequently.

The results of this study are important as guidelines for creating preventive programs that focus on the parents of children with developmental difficulties, which would promote and encourage them towards using desirable family coping strategies. Fur-

ther research should include both individual and family strategies of coping with stress caused by raising a child with cerebral palsy, so that the psychosocial programs could focus both on needs of the family as a whole, and on all its individual members.

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